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The right to take risks

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Abstract

Purpose – Commissioned as part of a Joseph Rowntree Foundation scoping programme, this consultation aims to explore the views of disabled people and service users about risk.

Design/methodology/approach – The consultation reached nine individuals and one focus group, reaching a total of 17 disabled people and service users. Their views were supplemented by the literature.

Findings – The landscape of risk and rights is highly complex. Disabled people and service users have quite different concerns about risk to those of the professionals and the regulatory bodies acting on their behalf. Many people talked of the fear of losing their independence, of asserting their rights and the fear of powerlessness in the face of bureaucracy and (sometimes) uncaring staff.

Research limitations/implications – The profile of rights needs to be raised in an accessible and acceptable way: it is necessary to make the language of rights more commonplace. There is a particular need to reach into mental health and residential care services to find ways of enabling people to have their rights realised. The report has implications for risk assessment and risk management as well as for the regulatory bodies responsible in adult social care. Raising awareness among professionals and policy makers about the risks that service users themselves fear and experience should demonstrate just how important it is that the people whose risk is under consideration are involved in the process.

Originality/value – This paper highlights the views of users of adult social care about risk; their views have rarely been documented.

Keywords Risk, Service users, Disabled people, Rights, Independence, Adult social care, Disabilities, United Kingdom, Risk analysis, Social care, Mental health services

Paper type Conceptual paper

Introduction

In 2011 the Joseph Rowntree Foundation commissioned the author to undertake a small scoping exercise: “to look across the landscape of adult (social) care and discuss service users” perspectives on salient issues associated with their right to decide about the risks they wish take in their lives, but also on their right to be protected from risks’. The full report of the consultation is published on the JRF web site (Faulkner, 2012). This paper outlines some of the issues in relation to risk, rights and responsibility.

In the field of adult social care, there are many people, issues, organisations and regulatory bodies involved in discussions about risk and safety. Questions of responsibility, duty of care, adult safeguarding and capacity come into play. There is the concern about protecting people society has come to perceive as “vulnerable” and yet these same people we want to be able to live full and independent lives and to take the risks that any one might take in an average day.

Practitioners’ views of risk often differ from the views of people using services and the language used to express risk also differs (Carr, 2010). These perceived risks have implications for the safety and the independence of the individual, but they also have implications for the

The full report from which this paper is adapted is published on the JRF website. Particular thanks are due to those people who generously gave of their time and their views in forming the basis for this project. Also to Ilona Haslewood and the Joseph Rowntree Foundation for initiating the project, and to those who commented on earlier drafts and helped to improve this report, particularly: Sarah Carr, Tina Coldham, Suzanne Collins, Dorothy Gould, Melanie Henwood, Ann Macfarlane and Kay Sheldon.

accountability of the care providers, perhaps for friends and family and for wider society. Consequently, the risk arena becomes contested by a number of different “stakeholders”.

The relationship between risk, empowerment and safety is a complex one. Adult safeguarding has traditionally been dominated by concerns about risk and safety; yet service users can lose out in other ways by overly risk-averse practice. In the consultation on “No Secrets”, many people said that they were offered safety, “often at the expense of other qualities of life, such as dignity, autonomy, independence, family life and self determination” (DH, 2009, p. 16). Concerns about risk can be used to block the involvement of people who use services in adult safeguarding (Wallcraft and Sweeney, 2011).

Within this broad debate, the voices of service users are rarely heard. In their UK-based scoping review of risk and adult social care, Mitchell and Glendinning (2007) found very few studies reporting only the views of service users. They suggest that this could reflect “the state’s role and pre-occupation with risk management” rather than with exploring and seeking to understand service users’ perspectives of risk. They highlighted the need for more research exploring user (and carer) perspectives. Their updated review (Mitchell and Glendinning, 2007) reports a few additional studies on the experiences of people with mental health problems, people with learning disabilities and older people. But significant gaps remain.

This paper sought to explore a few of those gaps with a small number of service users whose experience and expertise could shed some light on the dilemmas that arise from discussions about risk.

Methods

The main source of information for the paper was the views of a small number of service users and disabled people. However, these views were supplemented by reference to existing literature, particularly where it helped to amplify the voices of marginalised groups or issues not reached by the consultation.

Nine individual interviews and one focus group (with a JRF Service User Reference Group) were carried out, reaching a total of 17 people. These included disabled people, older people, people with learning difficulties and people with mental health problems. By observation only, the majority may be described as white British, two were Black African Caribbean.

Limitations of this study

This was a small consultation which aimed to explore issues of risk and responsibility in depth with a small number of service users. It is by no means a “representative” sample of the population of people who are covered by these issues. The consultation did not reach some people whose voices are seldom heard; for example, very frail older people or those with dementia living in residential settings; people with complex needs, severe learning difficulties or “challenging behaviour” living in residential settings.

A personal note

My own interest in carrying out this consultation arose from my experiences as a mental health service user over several years: experiences that include self-harm and taking risks with my own health and life. On this journey, I met a good friend and strong woman whose self-harm finally resulted in her death. This experience gave me a different perspective on my own risk-taking and on the risks that she was able to take whilst in extreme distress. I might have wished that someone had kept her safe even if against her will, but she would not have wanted that. As with many of the situations discussed during the course of my conversations with people for this project, these experiences illustrate the fact that thinking about risk often involves an engagement with complex dilemmas and an acceptance that there may be no ideal solution.

What are the risks?

Risk is perceived in different ways across and between different groups of service users and disabled people. The risk of potential harm and abuse underpins much of the discussion, particularly in the adult safeguarding arena where the protection of “vulnerable” adults is paramount. Different perceptions of risk are of particular concern in mental health, where people may fear for their personal safety at times of distress but tend to have the emphasis placed on the harm they might present to others (Sheldon, 2010).

For many of the people involved in this consultation, the risk of losing their independence was of greater concern than many of the potential dangers perceived or apparent in their lives. Some of the choices people were making to maximise their independence appear risk-averse, whereas others appear to embrace risk in the interests of asserting or maintaining their independence. Independence – having control over your life, having choices and being able to make decisions for yourself – is something to be preserved as well as fought for and can exist in a range of different environments. One disabled man described the importance for him of having a back-up plan should anything prevent one of his personal assistants from coming to work with him:

I have to be sure I've got the right support with me. It's my duty and my responsibility to get it right, to have the right personal assistance at all times. That would be my threat – people have accidents, get ill. I have to cover for that-it's something I have to be aware of, and come up with alternatives. I have to have it at the back of my mind all the time.

For many people, the potential risk to independence and quality of life is not apparently considered by social care services, or is not given the same weight as, for example, an assessment of the health and safety risks of going on a day trip. It was rare for staff or services to consider the consequences to an individual of not taking a risk. Preserving safety at all costs can mean not just the risk of reduced independence but also of increased institutionalisation, particularly – but not exclusively – for people in residential settings.

For some people, maintaining independence can mean managing issues that might appear small on the face of it, but which could affect someone's quality of life to a significant degree. Examples included being able to choose your own toiletries, the time you go to bed, whether or not to have a biscuit with your cup of tea. These examples appear to be the result of services imposing an institutional approach towards safety upon everyone without much thought given to the individual choice or consequences. The difficulty of negotiating these issues often led to considerable frustration, but could in theory be resolved with the use of common sense or relatively simple strategies. One example was given by a woman talking about her mother, who had smoked since she was 11 years old and wished to continue making the same choice:

She went to a day centre two days a week for about 9 months before she died; her dementia was still in the early stages but they would not let her outside for a smoke, which upset her... We as a family would have been happy to sign something to take responsibility for her being allowed outside to smoke. I felt her human rights were affected – she was happy to take this risk and so was the family.

Several people talked of the every day risks they faced simply by choosing to leave the house, go to meetings, take part in the community. Three members of a service user reference group talked of the challenges they faced by attending meetings. Two members usually travelled with a PA or supporter. One member of the group talked of the every day risk of bone fractures she faces in her decisions to go out, rather than to stay at home where she might be safe – but ultimately passive and powerless:

My whole life has been about risk management... When you have brittle bones you really don't have much choice about that... In the end after having lots and lots of fractures I had to think about how to manage this risk. It is real – I do have all these fractures. The risk assessment stuff became something I had to take control of...

The risks posed by contact with services were raised by several people, particularly in connection with residential care or mental health services. In both cases, the issue at the

heart of the discussion was power. One woman spoke of carefully measuring the information she gives to her GP for fear of the response if she told them how she was really feeling:

... because I'm terrified of the Mental Health Act and I know services in my area are not sympathetic. At the very time you need help most I have to be very careful and then maybe not get the help I need. It's a real Catch 22.

A couple of people talked about the vagaries of services; for example, hospitals being over-protective and concerned about discharging people, until they need a bed and then discharging them quickly without the same concerns in evidence.

The literature shows that people from Black and minority ethnic communities face increased levels of risk. The report *Inside Outside* (NIMHE, 2003) suggested that people from BME communities are much more likely to be assessed as risky to the public and as a result, detained under the Mental Health Act (1983), given more drugs by depot injections, and subject to more control and restraint when in hospital.

In a similar vein, lesbian, gay, bisexual and transgendered people can face risks from contact with services, particularly mental health services. Carr (2011) highlighted the potential risks posed by services which have historically stigmatised and diagnosed people on the basis of their sexual identity, and the need for safe spaces that this creates for people.

In this consultation, the risk of abuse was primarily raised in relation to people in residential care where there is the potential for abusive treatment to occur unobserved, although a couple of people talked of the risks of financial abuse for older people. However, the literature tells us that the potential for the abuse of people in vulnerable situations is much wider than this. For example, people living alone and in their own homes are also potentially vulnerable to abuse – from family members, PAs or carers and others (Faulkner and Sweeney, 2011). People with learning difficulties are at particular risk of bullying and abuse in the community (People First Lambeth, 2007).

Significantly, the risk of public abuse was also mentioned by study participants which they related to current media coverage given to accusations directed at disabled people of being “benefits scroungers” or of “faking it”. This, they felt, has heightened the risks for disabled people of taking part in their communities, threatening their independence and ability to take part in every day life, because of the reality of disability hate crime. A recent poll carried out by Scope (July 2012) found that 46 per cent of disabled people said people's attitudes towards them have got worse over the past year. About 73 per cent experienced the assumption that they do not work and 83 per cent said coverage about benefits scroungers can negatively affect attitudes. Disabled people also reported that they are increasingly confronted by strangers questioning their right to support. (www.epolitix.com/latestnews/article-detail/newsarticle/disabled-targeted-in-hate-crimes-every-day/).

As this report suggests, stigma and discrimination is perhaps the biggest risk to the lives of many disabled people, particularly people with mental health problems (Sheldon, 2010; Sayce, 2008) and people with learning difficulties (People First Lambeth, 2007). In addition, some people may also face the risks of racism and of other additional sources of discrimination both in the community and, potentially, within services.

Particular risks experienced by people from marginalised groups were touched on by Begum (2005) in a SCIE consultation. For some of the people in these groups, in particular homeless people and refugees and asylum seekers, daily life circumstances were described as “risky, unsafe and provisional” resulting in some very different perceptions of risk. The idea that people might worry if refugee and asylum seekers who needed social care took risks was considered to be quite strange.

Fear loomed large for many of the people in this study, particularly those in the group discussion. People talked of the fear of losing their independence, fears for their own safety, and, crucially, the fear of standing up for themselves or for their rights. They also mentioned the perception that frontline staff are often afraid of being held responsible should something happen “on their watch”. Hence members of staff will often act defensively, and may themselves feel disempowered in a situation that does not support them to take risks with and for their clients.

Nevertheless, the fear of retribution for service users in residential and mental health services is powerful, particularly for people who continue to need or live in that service. One man talked about the risks he faced in deciding to assert his rights in a residential care setting. He described being “punished” with unpleasant treatment by staff, something that ultimately resulted in a finding in his favour (by the local Adult Safeguarding Board) of “institutional abuse”. For other people, this happened on a smaller, if more insidious, scale:

When people go into residential care they are entitled to “pocket money”. They don’t always get it, some of the homes keep that, saying that it’s for toiletries. They don’t get the choice of buying the ones they want. I know a woman who put up with it because she was afraid. Her quality of life was affected. There’s a fear of asserting your rights.

These issues bring the theme of power and empowerment into sharp relief. The opportunity to make your own choices and decisions about your life relies on having the power to choose and decide.

Personal relationships

Some people talked about the complex association between risk and a range of different relationships. Examples were given of parents of disabled people or the children of older adults being overly-protective and wishing to curb people’s independence out of concern for their safety, often perceiving a greater degree of risk than might exist in reality. A member of the focus group talked of her family’s concerns about her taking the journey to meetings of a service user group:

Families can be very over-protective especially as you get older. I have a family who is very over-protective, but now they aren’t say anything to me because I say “this is my life and I’ll do what I want with it and if the day comes when I need your help I’ll ask for it”. . . They’ve had to get used to it. I’ve said if anything happens to me at a meeting or on my way to a meeting you’ll know I’ve died happily because I was doing what I wanted to do.

Whilst there was an association with fear, there was also an association with trust. If a relationship of trust existed between a person and their supporter, carer or personal assistant, reasonable risks could be taken that would promote or preserve an individual’s independence. Someone who genuinely listens and takes on board what the person has to say can build a relationship of trust and enable the potential for risk to be ameliorated.

Sheldon (2010) highlighted this issue of trust in her exploration of mental health service users’ experiences of risk and risk management:

When I got a new named nurse, she formed a good therapeutic relationship with me and wanted the two to one sessions to finish . . . I agreed to our one to one interviews being taped and then after a while the tape recording was not considered necessary any more [Service user quoted in Sheldon, 2010].

Finding a balance

Many people in this study talked in different ways about “weighing up” the risks of a particular endeavour, or of trying to find a balance between the risks and benefits involved in a particular decision or action. These might be quite small everyday decisions or major decisions and life choices. In some day-to-day decisions, this process could be quite a personal matter and might not reach the attention of services or professionals. However, for someone in residential care, this level of choice and independence was less likely.

A measure of risk inevitably contributes to the process of assessing someone’s right to services. One disabled woman talked of the complex balance she faced, between presenting enough of a risk to qualify for a service but not too much of a risk that she might be in danger of losing her independence:

When I have a care assessment I have to be careful how I talk about that stuff. . . you don’t get any service unless you are deemed at risk and social services put something into stop you being at risk, that’s the only basis on which you get a service. You have to play it carefully. You don’t want to be so at risk that you get put in residential care or not allowed out or something but you need to be enough at risk to get a service.

Some people's experience of this weighing-up process is that they are not allowed to participate in it – often it is being done by others on their behalf, as in the example of assessing the health and safety risks involved in going on a day trip for a group of people in residential care. This takes us into the realm of risk assessment and decision-making, which people felt often takes place without them and by people who are not directly affected by the risk. This was referred to several times in relation to people in mental health services, whether they represented a risk to themselves or to other people.

Excluding people from decisions about their own risks has implications, not just for the accuracy of the assessment, but also for people's dignity and human rights. Langan and Lindow (2004) and Sheldon (2010) showed how unreliable, inaccurate and out of date risk assessments in mental health can be, most of which did not consult with service users:

The only time that robust risk management surfaced, by all mental health professionals concerned [was] to protect themselves from possible recriminations and accountability. Never, during all this time, did one person stand up and ask "what are we doing to 'S'?" (service user quoted in Sheldon, 2010).

It has been noted in the literature that people going through the safeguarding process often have responsibility and even knowledge of what is going on taken out of their hands, as professionals act in response to a situation where someone has been abused (Wallcraft and Sweeney, 2011; CSCI, 2008a, b). In the consultation report on *No Secrets* (DH, 2009), people reported wanting help to deal with potentially and actually abusive situations in their own way. They wanted to "do their own safeguarding, they wanted help with information, options, alternatives, suggestions, mediation, "talking to' and so on" (p. 18). "They did not want decisions made for them".

This highlights the importance of people who are at risk having training and/or regular practice in making independent decisions. Although most of the research and practice to improve decision-making skills has taken place with people with learning difficulties, the importance of having the knowledge, assertiveness and resistance to defend oneself might reasonably be considered to apply to all adults in potentially risky or abusive situations (Faulkner and Sweeney, 2011).

Often this comes back to the culture and ethos of services. Trainers doing skills development with people with learning difficulties found that, if they returned to a service with a non-receptive culture, their skills would soon founder. If however they returned to a service that encouraged them to make regular day to day decisions for themselves, they would be more likely to be able to use their skills to protect themselves if the opportunity arose (reported in Faulkner and Sweeney (2011)).

Other approaches to finding this balance or to managing the situation of risk assessment with the service user include circles of support, family group conferences and risk enablement panels. Circles of support have largely been used in relation to people with learning difficulties, but they have been used with other groups too (Armstrong *et al.*, 2008). Risk enablement panels have been identified as emerging practice in relation to personalisation and self-directed support, as a way of helping with complex decisions that may arise in signing off a person's support plan (Carr, 2010). The emphasis here is on shared decision-making with transparent shared responsibility, including the service user and their carers, family or friends and in line with the Mental Capacity Act (2005).

Rights

Rights have to come first and the dignity to be able to take risks (Interviewee).

Rights might provide us with the means to address some of the fears and uncertainties about risk taking. For some people interviewed for this study, a rights-based approach was considered to be one of the ways of tackling this whole arena. One interviewee talked passionately about the potential of the UN convention on the rights of persons with disabilities (to which the UK is a signatory): particularly article 19 on the right to independent living. He was not alone in believing that the right to independent living for people with

disabilities needs to be enshrined in law. The UNCRPD has huge potential advantages for disabled people. The difficulty is fitting it within the framework of our existing national legislation, which is something that all signatories are expected to do. Sooner or later, he believes, people will be able to use the convention to challenge certain decisions or matters affecting their lives.

Several authors have advocated a rights-based approach towards risk and risk assessment, decision-making, towards adult safeguarding and towards care and support in general (Sheldon, 2010; Whitelock, 2009; Neil *et al.*, 2008). But what does it mean to take a rights-based approach? Sheldon (2010) argues that risk management in mental health should be based on promoting and protecting our rights:

We should have our rights explained, including our human rights. Risk management should not compromise our rights to dignity, privacy and respect.

Whitelock (2009), also writing about mental health, argues for a shift in focus away from viewing safeguarding as protecting “vulnerable” people from abuse, towards the principle of upholding everyone’s human right not to be subjected to inhuman or degrading treatment. Speaking on behalf of mental health charity Mind, she advocates a rights-based approach to adult safeguarding (Whitelock, 2009), the key to which is that all professionals involved in adult safeguarding ensure that service users are fully involved in the process:

A rights-based approach to safeguarding recognises that people have the right not to be subjected to inhuman or degrading treatment (Article three of the Human Rights Act 1998 (HM Government, 1998)) but also the right to respect for a private and family life (Article eight).

In reality, as we have seen, standing up for your rights can be risky in itself and can result in negative consequences. A wholesale shift in policy and practice must be necessary for this situation to change.

Even within the context of thinking about disabled people and service users, some people have different rights and different limits to those rights. Some are excluded from jury service, do not have equal access to voting, education and employment opportunities or standing for public office; and many disabled people (particularly those with learning difficulties and/or mental health problems) experience unequal access to primary health care (Morris, 2005). Even in comparatively minor matters, people may be singled out for different or limited rights. Sayce (2008) cites an example of a deaf woman being denied the right to adopt a cat by an animal welfare charity on the grounds that she would not be able to hear if it was distressed. The acquisition of a label can both unlock access to certain services and benefits and, at the same time, erect barriers to some significant rights and opportunities.

One of the interviewees spoke about the fact that mental health service users do not have the same rights as other people because there is the possibility of taking away our freedom and our physical integrity through the use of the Mental Health Act: detention and treatment without consent. “We don’t even have to have lost capacity for it to happen”:

My difficulty is that people with a mental disorder have a different set of rights. We are second class citizens, we can be locked up, we can be treated against our will. So to talk about independent living is a bit inappropriate for us as a group, well not inappropriate but misses the point.

Referring back to the evidence about risk assessment in mental health (that it is frequently out of date and inaccurate), we might conclude that it is all the more important to involve people in the risk assessments made about them, as well as to ensure that people are made aware of their rights.

Responsibility

Much of the discussion about responsibility in the present study was implicit in the dialogue about “finding a balance” or maintaining independence. However, a number of people used the word in connection with the control they assumed over their own lives. One interviewee talked of it being his responsibility to ensure that he has the right assistance, that he keep his

home safe for himself and his personal assistants. He also talked of the responsibility he assumes in the community for being in control of a powerful electric wheelchair:

It's my responsibility in the community or wherever I go. I could quite easily knock people over, cause all kinds of damage. I have to take that on board. If something happened it would be me who would be responsible.

One person talked of taking responsibility for her own risks and risk management, after a childhood of receiving mixed messages and living with fear. Another asked whether you have a responsibility to assert your rights in a setting where other people might not have the capacity to do so, but all are equally affected by having their rights compromised.

The promotion of choice and control, of more creative and positive risk-taking, implies greater responsibility on the part of the service user. It is quite significant that many service users and disabled people assume that it is their own responsibility to keep themselves safe (DH, 2009), and that "understanding what made them safe required understanding them as people – understanding their personalities, their experiences, their family relationships, their wishes for the future and their past histories of choices" (DH, 2009, p. 2.11).

Conclusions

The landscape surrounding risk and rights is immensely complex. One person's decisions can impact upon the choices of another, and the path taken following a difference of opinion is likely to depend upon who holds the power. The culture and ethos surrounding risk and rights, both in wider society and within individual services, is risk-averse with a tendency to blame individuals when something goes wrong. Despite the existence of policies about whistle-blowing, the overpowering culture is for individuals to fear standing up for their own or other people's rights.

This consultation reached a fairly small number of people, many of whom were and are actively involved in campaigning or influencing local or national policy and services in different ways. The report does not claim to be "representative" of the whole spectrum of views on these issues, but it does give voice to some important fears and concerns – some of which are rarely voiced.

Disabled people and service users identified some additional and different risks to those commonly identified by professionals and policy-makers. They also talked about fear. A significant fear for many people, particularly at this time of welfare reform and service cuts, reviews and reassessments, is the fear of losing their independence. This implies that, in order to be person-centred, individual assessments and reviews need to have independence as their starting point. Several people supported the view that the right to independent living for disabled people should be enshrined in law.

The consultation suggests that the profile of people's individual and human rights needs to be raised in an accessible and acceptable way. This consultation demonstrated just how difficult it is for people to assert their rights when in situations of powerlessness, which raises the question of how we as a society raise the profile of everyone's right to equal rights. The challenge is how to enable people to assert their rights without necessarily entering into situations of conflict: to make the language of rights more commonplace and accessible.

Different people have different levels of power over their lives, the decisions made about them and the risks they can take. We particularly saw this in relation to people in residential care and mental health services, but can also extend this understanding to people with severe learning or communication difficulties. Different methods need to be employed to enable people to take part in decisions about their lives and the risks they wish to take if they face these challenges.

Another perspective on power is the relative power differential between people in quite powerless positions; for example, a care worker who has little power or status nevertheless has the power to affect a service user's quality of life in quite significant ways. As we have seen, apparently small issues can assume a considerable significance for someone who is powerless and dependent on care.

One of the themes to emerge from this consultation is that the key issues around perceptions of risk and rights are significantly different for mental health service users: people are perceived as a source of risk first and foremost, rather than being considered potentially at risk in vulnerable situations. They appear to be overlooked by adult safeguarding practices; and their individual rights are compromised by the Mental Health Act 1983. There is a clear connection between perceptions of risk and access to rights: the more risky you are seen to be by others, the fewer rights you have access to.

Co-production, service user involvement and user-led approaches were proposed by several people as ways for ensuring that the vision and views of service users are encapsulated in any policy or service and the delivery, monitoring and evaluation of that service. User involvement in risk assessments and informed decision-making about risks surely should itself be a right.

Raising awareness among professionals and policy makers about the risks that service users themselves fear and experience will hopefully demonstrate just how important it is that the people whose risk is under consideration are involved in the process of risk assessment. It is vital that we hear more from service users and disabled people in this complex arena, not just about their (our) perceptions of risk but also about our views and perceptions of rights and responsibilities. We have a right to take many of the same risks as anyone else – and a right to have our rights recognised.

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